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– Project Director Larry Deutsch, MD, MPH

SUMMARY

Issues: Infants and children in many communities, particularly inner cities, are served by several medical institutions with advanced technical resources. Yet even with access to such facilities, rates of preventable morbidity and mortality remain high, particularly in urban and rural areas with multicultural and mobile populations.¹ Quality and consistency of primary care are often poor, especially in regard to continuity and coordination of care. Fragmentation of services with multiple-site use are common, and well organized health records are often unavailable.

Goals: With these problems in mind, the Children's Health Network formed as a community-based effort to develop and provide public domain computer-based patient record systems, particularly for infants and children in underserved areas and smaller institutions.

Funding: After receiving support from local individuals, institutions and agencies in the Hartford, Connecticut area, the Children's Health Network gained funding in 1993 as a Field Initiated Project, Special Programs of Regional and National Significance (SPRANS) grant, from the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA), U.S. Public Health Service.

Process: During its initial period, the Children's Health Network formed a Steering Committee for community input, and created several Work Groups for functions such as database development, clinical applications, technical design, confidentiality, and aggregate use of data. Guidelines were established for a uniform database with standard, controlled vocabulary, unique patient identification methods, and policies for system security and data privacy, including consent forms for parents and mature minors that permit or deny access to selected individuals or sites.

Product: Children's Health Network has developed software and begun pilot testing and evaluation with a linked school-based clinic and nearby hospital pediatric ambulatory department. Additional steps remain, including revisions, further testing, and formal evaluation. Recommendations for development and testing of computer-based clinical information systems for maternal and child health are presented in the conclusion of this report.

1. Background

Throughout the early 1990s, interest heightened in the use of computerization within the health sector, as had occurred for data storage and exchange in other sectors of the economy such as banking. The benefits of extending new information methods for patient care and public health were accentuated in the 1992 Institute of Medicine volume, *The Computer-based Patient Record: an Essential Technology for Health Care*. (2) This report presented advantages of, and barriers to, wider introduction of computer-based patient record (CPR) systems. It stressed the importance of computerization for good clinical care, linkage with outside sources for guidelines and decision support during the encounter, and its value to secondary data repositories and registries. Computer-based patient records can be much more, therefore, than a paper record faxed or imaged for storage.

A subsequent publication noted that little attention has been paid by the private or public sector to applications of the National Information Infrastructure (NII) to help communities automate and use local clinical data in aggregate for population-based functions of local public health and research:

...problems with fragmentation, lack of standardization, episodic data collection — and the fact that data for public health purposes are often collected separately and redundantly from encounter data in the medical treatment system — have exacerbated the burden and costs of collecting data, limited the linkability and usefulness of the data that are collected, and resulted in critical gaps. The development of logically integrated health information systems, in which information collected once can serve multiple purposes, has the potential to overcome some of the problems.”

(3) With these needs in mind, the Children’s Health Network formed as a community-based effort to develop and provide public domain, computer-based patient record systems, particularly to underserved areas and smaller institutions that lack means internally. After receiving support from local individuals, institutions, and agencies in the Hartford, Connecticut area, the Network gained funding in 1993 as a Field Initiated Project, Special Programs of Regional and National Significance (SPRANS) grant, from the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA), U.S. Public Health Service. During its initial project period, the Children’s Health Network formed Work Groups, developed first-version software, and began pilot testing and evaluation with a linked school-based clinic and nearby hospital pediatric ambulatory department. Additional steps remain, including revision, further testing, and formal evaluation. Recommendations for further development and testing of computer-based clinical information systems for maternal and child health are presented in the conclusion of this report.

2. The importance of accessible patient records for good primary care

Central features of primary care include integration of approach to health, including continuity, comprehensiveness, and coordination.(4) But for mothers, infants, and children in many central urban and remote rural areas, these features of integration are often lacking. For families with many different providers visiting sites with non-uniform charting methods, prior medical history from other institutions or even within the same site is often absent or incomplete during ambulatory care encounters.

Poor continuity and coordination of care occur especially among urban regions and minority populations in which individuals and families have encounters with many community health centers, hospital emergency and out-patient departments, school-based clinics, specialists, and visiting nurse services. Poor children are less likely to have a regular source of ambulatory care (RSAC) than non-poor, with less consistency in accessing routine and sick care.(5) A survey in Hartford showed that 67% of those at a major off-hours clinic usually attended a different facility for care, with 22% indicating no RSAC.(6) Integration and consistency may also be poor for children with special health needs (CSHN). In a changing financing environment with multiple managed care organizations and clinical providers, agencies, and governments, identification and definitional issues for CSHN include:

- ! absence of a common approach, making identification, referral, and coordination difficult
- ! difficulties in maintaining a stable database of CSHN, since many go on and off Medicaid
- ! confidentiality concerns
- ! problems in addressing co-morbidities and severity of conditions
- ! identification of children without severe health problems or who are not in special programs but who still require special attention and additional services
- ! costs associated with flagging Medicaid recipients enrolled in CSHN programs

(7)Thus, despite recent efforts to improve regular care and coordination within Medicaid and commercial managed care frameworks, provider relationships and coverage eligibility remain inconsistent for many families in underserved, impoverished, or special needs areas.

For improvement in quality of care, availability of health history during encounters has been shown to increase problem recognition, adherence of providers to clinical guidelines, efficiency of lab and procedure ordering, and production of prompts for compliance with preventive care guidelines. In the absence of continuity of provider, a computer-based patient record or summary can offer a family and provider data about prior visits within that site or, as networks and parent-held records become widespread, at other sites of primary or specialty care. An on-line clinical information system should present a problem list, growth chart, immunization history, medications, procedures, test results, diagnoses, and disposition. Thus, where continuity of provider is absent, a computerized ambulatory record will serve to improve continuity of record, leading to enhanced problem recognition and care coordination.⁸

3. From individual clinical care to a National Information Infrastructure:

Multifunctional data for decision support, public health, and research Uniform comprehensive computerized clinical records can serve both direct care and public health efforts at several levels:

1. Individual patients or families and their primary care or specialist clinicians
2. Primary health care sites and other service or data locations
3. Local communities, including municipal and state health departments, school systems, specific databases, insurers
4. National health funding and research agencies

But computerization and electronic sharing of medical records is not yet widespread in the United States. Scattered and non-standard data are found in heterogeneous sites having widely different types of paper charts or management information systems. For community-level maternal and child health services, information for clinicians and local public health officials is hard to gather and analyze reliably. Redundant data entry for clinical records, forms, surveys, and external monitoring adds to burdens of clinical and public health practice.

Without comprehensive clinical information systems, coordination of services is difficult. Of surveyed state Title V programs, three-fourths are able to obtain data from other programs such as vital record, Medicaid, and immunization sources, but less than one-fourth can link data to Title V records. (9) In addition, health services research is hampered, particularly for longitudinal studies. Narrowly focused disease process or outcome studies have been less helpful than views derived from a comprehensive data sets. (10) Information from claims-payment databases is less reliable than from clinical information systems. (11) Planners and researchers are thus limited in conducting outcome studies, public health surveillance, and program evaluation as medical knowledge and financing methods evolve.

Obstacles to adoption of uniform, shared computer-based records are numerous. There has not been full acceptance of a core data set with common definitions and vocabularies, and the lack of unique identifiers impairs the collection of longitudinal and aggregate data. Standards for transmission between distinct databases, such as those for children with special needs, lead or immunization registries, WIC, injuries, AIDS, or prenatal care, remain under discussion, as are regulations and standards within and among states for assurance of confidentiality. For efficient linkages between clinical and administrative databases, political obstacles often loom larger than technical issues to improve coordination of services and monitor health outcomes among programs.

Among commercially developed medical practice systems, most have been designed for office-based management functions such as billing, scheduling, documentation for quality studies and monitoring agencies, etc. Some have standard relational databases permitting custom report generation, but many proprietary systems allow alterations in database fields, vocabularies, and reports only with the vendor's customization. Some have modules or other optional features for specialized functions (e.g., drug references, special report forms). These systems may perform

well within a single site or integrated information network, but do not allow ready access from other sites or databases without programmed conversion routines.

For sharing data across sites, efforts such as WEDI (Workgroup for Electronic Data Interchange) have proceeded from practice management and insurer needs for billing and monitoring purposes, rather than offering on-line information during clinical encounters or data availability for aggregation and research.

How can a clinical information system serve multiple functions — supplying appropriate clinical data for diverse applications and incorporating information from local epidemiological or national knowledge-based sources for decision support?

Visions have been described of a National Information Infrastructure (NII) in which computers, community networks, supporting software, and human interface would be linked nationwide to support rapid processing and exchange of information and improve productivity and the quality of life:

- ! Point-of-care information systems would supply data for clinical and administrative purposes through NII
- ! Physicians and patients would use clinical decision-support systems reached through the NII
- ! Rural and inner-city urban practitioners and their patients would have access to the most current medical knowledge and expert consultants through the NII
- ! Medical technology choices could be supported by scientific studies of specific conditions in the community, based on data collected through the NII
- ! The public health status of communities could be regularly assessed, using health and social indicator information generated through the NII
- # Challenges to fulfilling this vision of a National Information Infrastructure include:
 - # developing standards for patient care data
 - ! developing and implementing a system for unique personal identification
 - ! producing models to guide the flow of patient care data and information
 - ! enacting federal confidentiality and privacy laws to protect personal health data
 - ! experimenting with repositories of health data to learn their benefits and drawbacks
 - ! undertaking health care computer laboratory (test-bed) development
 - ! funding pilot tests and systems evaluations¹²

Recent legislation addresses several of these needs. The Health Insurance Portability and Accountability Act of 1996 (HIPAA, PL 104-191, Kassebaum-Kennedy) provides for:

- ! development of universal health care ID numbers for individuals, providers, plans, and employers
- ! recommendations for uniform code sets and classification systems through the National Committee on Vital and Health Statistics (NCVHS)
- ! electronic transmission standards for medical care encounter data by February 1998
- ! establishment of standards for confidentiality/security and penalties for breaches

Details are available through Department of Health and Human Services (DHHS) Web pages.

(13) For regional information support and exchange, development of Community Health Information Networks (CHINs) has been much discussed, but less often successfully implemented. Although technical solutions in client-server architecture and intranet designs are available, contextual factors are preeminent when several organizations are involved and have been modeled to understand and overcome these obstacles. Pioneering efforts to plan and implement CHINs have been described for different regions (Indiana/Michigan; Syracuse, New York; Santa Cruz, California), organizations (Veterans Affairs, integrated delivery networks), and specialties (perinatal care, HIV population, adverse drug reactions, child health indicators immunizations).(14)

4. Process: Guidelines for building a local database for children's health

Before expecting change in local practices of record keeping and sharing, a process of consensus-building should be developed among clinicians and institutions for uniform, transmissible, multi-purpose data in the community.

This multi-disciplinary group should set out to: 1) define the problem in local application and in general; 2) gain wider recognition of the need for these innovations for quality and efficiency in children's primary care services; 3) evaluate and implement a prototype clinical information system; 4) begin a process for further development, including enhanced decision support functions and ability to share data across heterogeneous institutions as technical means (direct, phone, cable, Internet) evolve; and 5) set the stage for continuing production, enhancement, revision, and distribution of such a clinical and public health tool in the public domain. In developing shared, uniform, patient-centered clinical information systems, it is apparent that national standards are lacking, although provider and administrative organizations, public agencies, and public and private payors are active in addressing these issues:

- a. uniform core data set and standard vocabularies for ambulatory care; uniform standard but locally adaptable/flexible
- b. unique identifier
- c. standards for data recording and transmission
- d. assurance of confidentiality – (See companion paper: B. Blechner, MCHB, 1997)
- e. system design and implementation – any system made widely available at sites small and large should incorporate design features which make it simple to install and operate; user-friendly; appropriately accessible to families, providers, and public health agencies; and inexpensive

4a. Uniform core data set for ambulatory care

A uniform ambulatory care data set (UACDS) has been proposed by the National Committee for Vital and Health Statistics (NCVHS) of the National Center for Health Statistics (NCHS) in several versions during 25 years, most recently in its Core Health Data Elements: Report of the National Committee on Vital and Health Statistics (8/96). (15) Its latest 42 elements (1996) are listed in full below. The Children's Health Network software began with an earlier, briefer NCVHS set of 16 core elements, and added fields that are important in delivery of ambulatory child health services.

Core health data elements proposed (August 1996) by NCVHS for standardization:

1. personal/unique identifier +++
2. date of birth +
3. gender +
4. race and ethnicity +
5. residence +
6. marital status +
7. living/residential arrangement ++
8. self-reported health status +++
9. functional status +++
10. years of schooling +
11. patient's relationship to subscriber/person eligible for entitlement +
12. current or most recent occupation and industry +++
13. type of encounter +++
14. admission date (inpatient) +
15. discharge date (inpatient) +
16. date of encounter (outpatient and physician services) +
17. facility identification ++
18. type of facility/place of encounter ++
19. health care practitioner identification (outpatient) ++
20. provider location or address of encounter (outpatient) +
21. attending physician identification (inpatient) ++
22. operating clinician identification ++
23. health care practitioner specialty ++
24. principal diagnosis (inpatient) +

- 25. primary diagnosis (inpatient) +
- 26. other diagnoses (inpatient) +
- 27. qualifier for other diagnoses (inpatient) +
- 28. patient's stated reason for visit or chief complaint (outpatient) +++
- 29. diagnosis chiefly responsible for services provided (outpatient) +
- ++ Substantial agreement has been reached, but some additional work is needed.
- +++ Recognized as significant, but considerable work remains to be undertaken.
- 31. external cause of injury +
- 33. principal procedure (inpatient) +
- 34. other procedures (inpatient) +
- 35. dates of procedures (inpatient) +
- 36. procedures and services (outpatient) +
- 37. medications prescribed +
- 38. disposition of patient (inpatient) ++
- 39. disposition of patient (outpatient) +
- 41. injury related to employment +
- 42. total billed charges ++
- + Ready for implementation.
- ++ Substantial agreement has been reached, but some additional work is needed.
- +++ Recognized as significant, but considerable work remains to be undertaken.

Health data elements (several fields each) added by Children's Health Network for maternal and child health clinical information system:

- ! Additional demographic data, pick lists, or text fields for: type of residence, phone, family members, prenatal and birth data
- ! Regular source of ambulatory care (RSAC) (medical home)
- ! Health maintenance: a. immunization status; b. screening status (lead, etc.)
- ! Growth (height, weight)
- ! Medication detail (dose, duration)
- ! Allergies
- ! Dental care, provider
- ! Development/education: school setting (level, teacher), days absent

Notes to NCVHS data set, some with CHN amplification:

- 1. Elements 1-12: Personal/enrollment data, do not need re-collection at each encounter except Element 1, the personal/unique identifier (See 4b. Unique identifier).
- 2. Elements 13-42 are encounter data, to be collected at each ambulatory, hospital or other health care encounter. (cont'd)

Element 4: Race and ethnicity. NCVHS expanded the definition slightly beyond those for collection by the federal Office of Management and Budget (OMB). Race (self-reported) includes 1. American Indian/Eskimo/Aleut, 2. Asian/Pacific Islander, 3. Black, 4. White, 5. Other (specify), 6. Unknown/not stated; Ethnicity lists 1. Hispanic (specify), 2. Other (specify), 3. Unknown/not

stated. Customization for local population demographics may be important for community data and program development, so that subcategories within a computerized picklist (drop-down box) or other options may be entered into a field to fold into OMB-reportable categories. Examples are: Southeast Asian/Cambodian, Southeast Asian/Vietnamese, Southeast Asian/Lao, (included within Asian); African-American, Caribbean/West Indian, African (within Black); and Latino/Puerto Rican, Latino/Mexican, Latino/Cuban or Dominican, Latino/Central or South American (within Hispanic). Collection of this element, as NCVHS notes, may, in conjunction with socioeconomic data, allow tracking of health status of minorities during changes in the U.S. health care system. Current federal consideration is being given to inclusion of “multiracial” or “mixed” categories

Elements 24-26, 29-30: Diagnoses, problems, or assessments for which the NCVHS currently recommended coding instrument is ICD-9-CM. With commonly available software, a diagnosis may be entered by clicking, scrolling, or typing initial letters within a standard controlled clinical vocabulary. This may be a full or modified ICD-9-CM list incorporated as a reference file by the Database Manager through a CIS maintenance function. As ICD-10-CM is released, other coding instruments are adopted by agencies or standards organizations, or as local issues suggest additions, the modification of coded vocabulary should be easy.

Element 28: Patient’s stated reason for visit (“chief complaint”). There is not one agreed-upon coding system. One, widely used in Europe and easily incorporated from disk as reference file for this field, is the International Classification of Primary Care (ICPC). (International Classification of Primary Care. Henk Lamberts and Maurice Wood, eds. Oxford University Press, New York, 1987.)

Element 31: Inclusion of E-codes (using ICD-9-CM coding) is important for study and intervention related to cases of injury or poisoning. Its use is required in some states and facilities, but is not yet universal.

Elements 33, 36: For inpatient procedures (33), ICD-9-CM vol. 3 is required, while for outpatient procedures (36), the Health Care Financing Administration (HCFA) Common Procedure Coding System (HCPCS), based on Common Procedural Terminology (CPT-4), is required. A single system is advocated by NCVHS.

Element 39: Disposition (outpatient) is, for maternal and child health providers, a crucial field for indicating and monitoring ongoing needs and problems for follow-up. The field may include: no follow-up or PRN return; scheduled follow-up; or referred elsewhere. This field within an abstracted medical record is key to several important functions: creation of automated mailed or phoned prompts for next well-child visits, immunizations, and special appointments.

The purpose of the NCVHS proposed set is “to improve the efficiency and effectiveness of the health care system,” and anticipates requirements of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (Kassebaum-Kennedy), by standardizing information for resource allocation, for quality assurance and surveillance, and for knowledge development (i.e., evidence-based medicine). “Administrative simplification is made imperative by recent health care

system changes such as increasingly fluid boundaries between sites of care, melding of administrative and clinical data, and need to monitor the shift of responsibility for vulnerable populations to the private sector.”(16)

Common clinical vocabularies and coding systems (including ICD-9/10-CM, SNOMED, Read, and ICPC) are being evaluated by numerous researchers and the National Library of Medicine (NLM) Metathesaurus Project.

4b. Unique identifier

Lack of a generally accepted unique identifier in the United States has been a major factor in limiting computerization and sharing of clinical data among health service sites. A common recommendation at this time, from the NCVHS and the Computer-based Patient Record Institute (CPRI), is the Social Security Number (SSN), modified with addition of birth date, security digits, or encryption. Limitations include assignment of numbers for newborns, linkages for family tracking, misuse or duplication, and designations for non-citizens.

Other systems have been advanced using existing data elements for linkage purposes. The California State Department of Health has accepted for uniqueness and accuracy a combination of five items: birth name, date of birth, place of birth, gender, and mother’s first name, with other items added for confirmation. For sub-populations receiving public services, Medicaid numbers have been used to correlate services among different sites, but obviously these may change depending on eligibility. Similarly, those within managed care networks — or having other insurance — may have identifiers that vary over time, depending on employment or other coverage changes.

As noted above, the recent HIPAA of 1996 requires adoption of standards for these unique identifiers.

4c. Standards for data recording and transmission

For extension of computerized clinical information systems among community health sites, lack of uniform standards for data recording and transmission among various sites has been a major stumbling block. Various standards development organizations (SDOs) and agencies are dedicated to establishing and implementing standards for definitions, transmission, and security for medical data exchange within and among community health centers, school-based clinics, hospital data systems, laboratories, and public health agencies. With leadership from the Agency for Health Care Policy and Research (AHCPR), standards for administrative electronic healthcare data transactions are under study by the American National Standards Institute (ANSI) and its Healthcare Informatics Standards Board (HISB); IEEE; X12; ADA; and (in Europe) the Comité Européen de Normalization (CEN), Technical Committee (TC) 251 (medical informatics). In addition, Health Level 7 (HL7) is releasing a new version (2.3) with transaction standards for data exchange among primary care providers, specialists, payors, and labs, and has worked with the Centers for Disease Control and Prevention to support needs of public health organizations in community and state databases, such as immunization registries. (17)

4d. Assurance of confidentiality

Many maternal and child health projects seek to share data on those infants, children, and adolescents who have more than one health provider. Ensuring privacy and confidentiality has been raised from the start as a key issue. Early effort should include discussion of the following issues:

- ! What data should be collected? Comprehensive medical data, all regarded as confidential, should be stored in a relational database, accessible only through readily available software techniques for ID names and passwords of authorized users.
- ! Where should data be stored? Data can be stored and firewall-protected within a server at the local facility identified by the patient or family as their RSAC (medical home). This is a distributed rather than central-repository model. Growth of wide-area networks with many facilities would necessitate a master-patient index (MPI), rather than polling or creation of a single central repository.
- ! Who should control data release? Parents (or mature minors) should have authority to allow or deny transmission of medical data to remote networked sites through formal consent forms distinct from routine permission signatures for medical record release. They may also be offered a hard-copy printout of summary data as a hand-held record.
- ! How should data be transmitted? Sites may be linked with a direct 56Kb line, avoiding many security issues. With development of Internet linkages between client-server or intranet-structured sites, advanced encryption and password methods should be employed, according to emerging national standards through HIPAA legislation or new standards development organization recommendations.

The National Research Council has released a report (March 1997) with recommendations for national policy for security in electronic records and accountability for secondary use of health data. (18) For pediatricians in practice, safeguards for storage and transmission of electronic medical records or faxed messages have been described by the American Academy of Pediatrics. (19) See the companion paper on confidentiality for a full description of research and innovation by Task Force members and legal consultants for Children's Health Network. (20)

4e. System design and implementation: Technical feature simple, accessible, adaptable, inexpensive; active decision support — CPR not just a typed paper chart

In designing an information system for primary care pediatrics, important goals are the improvement of continuity and coordination using on-line data shared with consent during clinical encounters. To improve decision-making, treatment planning, and follow-up, reference services from local or national sources should be made available to community-based providers in smaller sites still lacking them. Such services include Grateful Med of the National Library of Medicine

(NLM) (21) and guidelines made available on the Internet through the Agency for Health Care Policy and Research (AHCPR) and professional groups.

To support ambulatory needs in an environment where services and data are dispersed among many sites, unique requirements exist that have not been incorporated in many traditional patient record systems. An information strategy in this setting emphasizes the storing and transmission of clinical information across heterogeneous sites with distributed databases and differing institutional needs.

System requirements should thus include:

- ! access to any child's record from other locations
- ! security of equipment and data while sharing information across sites
- ! ability to update records stored at designated Regular Source of Ambulatory Care (RSAC) after each clinical encounter
- ! minimal maintenance effort needed to ensure accurate and compiled data
- ! use of inexpensive hardware and software linked through readily available phone or cable lines
- ! availability of on-line services (such as guidelines, health data, processing routines, and interactive decision support)

The system design should accommodate flexible data entry techniques and formats. Entry capabilities and preferences differ among sites, and such preferences should be elicited as planning for a clinical information system proceeds. Some prefer direct provider entry during or after an encounter, through mouse selection among buttons or drop-down lists, or keyboard scrolling and text entry. Other sites may choose to have data entered from controlled vocabularies or text by clerical staff following a visit. For either, availability of pen and voice entry for inexpensive and mobile ambulatory applications will continue to increase.

A clinical system will not be readily accepted without capacity to produce useful analyses and reports for health providers, reviewers, funders, and recipients of care. For maternal and child health, standardized report functions should include generation of immunization, school, and other forms, as well as generation of data for billing and external agency monitoring. A significant innovation of a patient-centered, site-driven computerized system is the potential for rapid production of patient-held records. This would enable families to have access to, and control over, their records — sharing information as they see fit, whether or not network linkages are present at a given site.

Additional value-adding functions should include export and interpretation of selected field data for linked modules, for purposes such as prompt generation with letter generation or automated phone calls through Telefinder or other systems.

Flexibility is needed while standards for Internet transmission become established. As heterogeneous sites and computer systems are linked, new interfaces must be created. In a rapidly changing field, detail is not possible here. Recent reports describe World Wide Web interfaces among major hospital emergency departments with different systems. (22)

5. Design of the Children's Health Network

To improve quality and efficiency in ambulatory care for infants and children in the Hartford, Connecticut region, a Children's Health Network (CHN) Task Force was formed including providers, academic and hospital-based information system (IS) experts, a school system administrator, and local and state health department representatives.

For CHN, consensus was gained to design overall features (architecture, database contents, institutional roles, confidentiality measures) and to apply for funding from local foundations and federal (MCHB) sources. For initial organization and allocation of work, the Task Force developed a Steering Committee for broader community input, with several Work Group functions such as database development, clinical applications, technical design, confidentiality, and applications of data for aggregate or community purposes.

Designers for the CHN Project adopted criteria to permit easy installation and use for flexibility and scalability. An open-architecture approach uses a client/server design with inexpensive PC (IBM-compatible) hardware and commonly available software. To allow a range of networking configurations, Windows NT permits accommodation of near and remote clients linked through one or more servers. Linkage design initially uses a direct line (56 Kb), with ISDN as a second alternative. A server at each major site would permit "firewall" construction for institutional data control and security in regulating outside access.

The designated RSAC maintains a composite record in its server's relational database. For record linkages, network server-server polling is planned, using unique health identifiers (UHIs).

In this period prior to UHI implementation in accord with HIPAA legislation, minimum sets of individual demographic data, as discussed above, are used. For the Children's Health Network, patients can be found by name or identifying number — Medicaid, CHN-specific, or hospital, as examples. Confirmation of identity when individuals with the same name are found appears, showing birth date, place of birth, and grade in school. With system growth to region-wide proportions, master patient indices will be developed. Approaches include Web tools such as the MPI mediator of the CPRI (Computer-based Record Institute) and a Community Persons Index (CPI) envisioned by the Minnesota Health Data Institute. (23)

Privacy of individual patient data in CHN is protected by having parents or mature minors sign specifically written consent forms; these permit or deny access through the server to selected individuals or sites other than their primary care provider. The database records person and time of signature, and when renewable (duration of consent). Once a record for an individual patient is entered, screens with clinical information show an ID number but not a name for added data security from casual viewing. Software supports an audit trail for each entry or view.

For data entry and summary review, separate applications were developed, allowing distinct data viewing and entry capability for designated system users, by user name and ID, depending on "need to know" and administrative or clinical role. Powerbuilder 4.0 was the initial CHN selection

for screens and data access functions, with data residing in a Watcom SQL relational database. Both are sufficient for most smaller sites; as future needs and versions appear, either can be replaced by other front-end or database software accommodating similar fields and reference files and operating within a networked configuration.

Screens for data entry are divided broadly into demographic and clinical sections. Initial and succeeding screens within the Powerbuilder program have fields for keyboard text entry or mouse- or pen-selected pick list (drop box) selections. Many demographic and clinical fields associated with controlled-vocabulary selections have text entry options.

Demographics are viewed and entered with an initial summary screen and detailed screens with direct entry for names, addresses, parents, and comments about family, with mouse selection from locally designed reference lists for type of residence and phone, race, clinic site, local provider, dentist, pharmacy, etc.

For clinical encounter data, an initial clinical screen captures, date, time, type, provider, and height and weight at the encounter. The following screens each have several fields for mouse-selection and text entry. The first, reason for visit, offers scrolling (with first-letter pointing) of text and code list of the International Classification of Primary Care (ICPC), a coding system which many believe offers the best representation of presenting symptom ("chief complaint"), closest to patient's description, as well as specific diagnostic codes which map to ICD-9-CM. Text entry gives opportunity for more complete description of the presenting history. In this ("encounter entry") and data summary ("review") modes, reasons for visit from prior encounters are shown.

Subsequent clinical encounter screens allow selection from controlled vocabularies with text and numerical entry for test and screening procedures, by CPT codes and customized additions, with fields for result entry and comments for interpretation and follow-up. ICD-9-CM text and codes, with selected additions, are used in fields for diagnosis. A locally composed reference file of most commonly used pediatric medications, doses, and schedules was entered, with text-entry capability as well. Import of a longer commercial list for selections is an alternative.

Data in these fields are suitable for export from this relational database to others within billing and administrative routines, and for inclusion in standardized or customized reporting formats. Additional screens accommodate entries for provider-entered problem list, disposition (follow-up), specific program participation (WIC, developmental, social service), allergies, and others. Each is summarized (with dates and text, and different sort options) in the review mode, with variable Windows presentations.

From its SQL database, the system will be able to generate customized reports for administrative analyses, tables for research studies and grants, and hard copy or electronic export to public agency, insurer, regulatory, or research data units.

6. Conclusions, recommendations, policy implications

As with other projects with long-range goals, the Children's Health Network course has been subject to changing conditions. Since inception, there have been variations in institutional commitment, data and technical standards, and legal guidelines. But the solid goals of improving quality of ambulatory care and information about maternal and child health services for underserved areas, for minority populations, and for children with special health needs, remain widely accepted.

Objectives toward reaching such solid ground should include national and regional programs to modernize information systems, including a public-domain, computer-based information tool for clinical and public health practice in maternal and child health. Toward reaching this ground, the following six recommendations are made:

- ! Sustain funding for strong community-based primary care sites, such as community health centers, school-based clinics, and home-visiting services, including budgets for modern comprehensive clinical information systems with linkages to regional and national health information infrastructures.
Invest in a variety of community-based demonstration pilots which test comprehensive clinically driven information systems that yield multi-functional data for direct service, public health functions, and research. These systems are distinct from management information systems primarily for fiscal and administrative tasks.
- ! Make available, for all ambulatory care providers, standard, flexible, regularly revised public-domain software, including features to develop parent-held records and to ease burdensome efforts to produce reports for quality monitoring, external agencies, and multiple payors.
- ! Supply and maintain networking equipment including linkage hardware, means for secure connections, and conversion software to accommodate new and legacy systems, with stand-alone versions for remote or non-networked sites.
- ! Expand, through the NII and local networks, on-line cost-free interactive decision-support and reference services from the National Library of Medicine and regional academic medical centers.
- ! Assure ongoing technical assistance through state or federal sources to smaller sites lacking internal information department expertise, especially to meet changing external monitoring and data reporting requirements and to adapt to technical advances.

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8. Additional sources of information

- ! MCHB: MCH-NetLink: www.ichp.ufl.edu/MCH-NetLink; E-mail directory, <http://www.os.dhhs.gov/hrsa/mchb/>; E-mail address: ichp@qm.server.ufl.edu.
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- ! Toward a National Health Information Infrastructure: Report of the Work Group on computerization of Patient Records to the Secretary of DHHS, April 1993.
- ! Computer-based Patient Record Institute: 1000 East Woodfield Rd, Suite 102, Schaumburg, IL 60173-4742, (708) 706-6746.
- ! Data Utilization Skills Development Initiative project: A. Farel, DrPH, Univ. of North Carolina (Chapel Hill), School of Public Health, CB# 7400, Rosenau Hall, Chapel Hill, NC 27599-7400.

9. Acronym Glossary

AHCPR: Agency for Health Care Policy and Research, PHS
AMIA: American Medical Informatics Association
ANSI: American National Standards Institute
CDC: Centers for Disease Control
CEN: Comite Europeen de Normalisation
CHIN: Community Health Information Network
CHN: Children's Health Network
CIS: computer information system
CPI: Community Persons Index
CPR: computer-based patient record system
CPRI: Computer-based Patient Record Institute
CPT: common procedural terminology
CSHN: children with special health needs
DHHS: Department of Health and Human Services
HCFA: Health Care Financing Administration
HCPCS: Health Care Procedure Coding System
HISB: Healthcare Informatics Standards Board
HIPAA: Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191)
HL7: Health Level 7
HRSA: Health Resources and Services Administration
ICPC: International Classification of Primary Care
IOM: Institute of Medicine
IS: Information system
MCHB: Maternal and Child Health Bureau, PHS
MPI: Master patient index
NCHS: National Center for Health Statistics (NCHS)
NCVHS: National Committee on Vital and Health Statistics, National Center for Health Statistics, PHS
NII: National Information Infrastructure
NLM: National Library of Medicine
OMB: Office of Management and Budget
PHS: U.S. Public Health Service, Department of Health and Human Services
RSAC: Regular source of ambulatory care (medical home)
SDO: standards development organizations
SPRANS: Special Programs of Regional and National Significance
SSN: Social Security Number
TC: Technical committee
UACDS: Uniform ambulatory core data set
UHI: Unique health identifier
WEDI: Workgroup for Electronic Data Interchanges
WIC: Women, Infants and Children program